

July 1999

Clinical Center News

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Starbright World debuts at Clinical Center

In a world where pain and fear are real, a world where disease is as much a reality as the sun, all of us can use a little escape now and then. But for children in a hospital, how do they escape?

The Starbright Foundation and the persistence of NCI's Dr. Lori Wiener have made it a little easier for the children of the CC to escape – to Starbright World.

Starbright World is a private, interactive computer network specially designed for hospitalized children and teenagers. It is a place where children with serious and chronic medical conditions can interact with a community of peers from across the nation, helping each other cope with the day-to-day realities of life with illness.

Steven Spielberg, Academy Award-winning filmmaker and chairman of the Starbright Foundation, envisioned this escape for kids, hoping to create a virtual play haven and tool for children to cope with serious or chronic illness.

"Maybe it's just for an hour during the day, but for that hour, kids can escape from their pain and their reality to a place where they can make anything happen," said Spielberg. "They are in total control, and we can give them a place where their imaginations can run free."

Dr. Wiener, coordinator of the pediatric HIV psychosocial support program and of Starbright World here at the CC, was asked to review grant proposals analyzing Starbright World and its effects on children. She was able to use her existing knowledge of the program and her relationship with the Starbright World staff to bring the program to the Clinical Center.

She also credits the support of CC Director Dr. John Gallin and NCI Deputy Director Dr. Al Rabson as crucial to making the project happen.

"The Starbright World has already brightened the world for the Clinical Center's youngest participants in clinical research," said Dr. Gallin. "We are fortunate to have



CC patient Heide Rodriguez (center) chats with a patient at another hospital via Starbright World's videoconferencing feature. A small camera, visible just underneath the computer's monitor, enables Heide and her long-distance friend to see each other while they talk. Dr. James Taylor, of NCI's pediatric oncology branch, and friend Lakeisha Grant look on.

See *Starbright*, page six

Alternative Work Schedules: Why Not Me?

Recently the CC Quality of Worklife Council received the following suggestion:

The suggestion:

My quality of life would be improved a lot if I could work a flexible schedule. A lot of people in the Medical Record Department want to do this but the director of the department will not let it be. He has said no for years. We are the only employees in the Clinical Center that can't have this benefit.

The response:

The Medical Record Department (MRD) is not the only department at the Clinical Center that does not use flexible work schedules. The MRD provides direct customer service to health care practitioners, researchers, CC administration, Institute staff, and patients. Routine hours of operation are 8:30 a.m. to 5 p.m. in all sections, except the Record Management area (files area), which is open from 7 a.m. to 7 p.m. It is essential that adequate MRD personnel be at work on a continuous basis to serve customers when the majority of other CC/NIH departments and offices are open for business. Since many of the functional sections of the department have relatively few employees, it is extremely problematic to accommodate flexible work schedules, considering sick, annual, and administrative leave absences, along with routine vacancies. It is already a real challenge to maintain a

critical mass of employees for every workday, within the core hours of operation for each section. Flexible work schedules would make it even more difficult to maintain continuous, uninterrupted, high quality customer service. However, employees experiencing unanticipated hardship, directly related to the work schedule, are encouraged to discuss their situation with their supervisors to see if there are potential options for temporary fixes while the problem continues, without unduly compromising the capability of the section to accomplish its tasks.

More information from the Council

Alternative Work Schedules (AWS) are scheduling options that are available to Clinical Center employees if adopted and approved by management. AWS involves different types of workweeks other than traditional schedules (8 hours per day/40 hours per week, with fixed starting and quitting times). In many cases, use of AWS permits employees to save leave by making appointments, taking classes, or pursuing other personal needs during "core" hours.

Because of patient care and research priorities or other circumstances, however, it is not always possible to afford employees the opportunity to participate. While a number of CC departments use AWS in a permanent or temporary capacity, other departments do not. Employees who seek AWS should discuss this

with their supervisors to determine if it is possible, or if other options may be considered to accommodate employee needs. The OHRM website has additional information on this topic (<http://ohrm.cc.nih.gov/site/information.html>). Also, there are AWS informational brochures on the first floor, Bldg. 10, in the atrium area, and in the lobby of 6100 Executive Blvd., first floor.

Classes offered

The Clinical Center Quality of Worklife Council would like to remind employees about upcoming family supportive classes being offered by the Education and Training Section of the OHRM. Classes are free to CC staff and are held in Bldg. 10, Lipsett Amphitheater. Call 6-1618 to register.

Child Care Options: An Educated Decision, Aug. 11, from 9 a.m. to 11 a.m. Register by July 21.

Personal Financial Management, Aug. 26, from 9 a.m. to noon. Register by Aug. 5.

De-Stressing for Adults and Children, Sept. 22, from 9 a.m. to 11 a.m. Register by Sept. 1.

Clinical Center
News

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Talent wanted

The CC Workforce Diversity Advisory Council is looking for in-house talent to help entertain during an upcoming diversity program. The Council hopes to showcase a variety of talent from the diverse population of the CC. All are encouraged to participate. For more information, or to volunteer your special talent, call Carl Lucas at 6-1584.

Heart disease study

The Heart Disease Risk Factors in African-Americans Study seeks new participants for a study of the relationship between obesity and heart disease risk factors in healthy, nondiabetic African-American men and women. Participants can be of normal weight, overweight, or obese and between the ages of 18 and 55.

Specifically, the study is looking at risk factors for triglyceride concentration and the triglyceride-related risk factors of "unhealthy cholesterol" (low density lipoprotein), "good cholesterol" (high density lipoprotein), and body fat distribution.

There will be a series of four outpatient visits to the Clinical Center, in which participants will have body fat analyses, an electrocardiogram (EKG), blood tests, including cholesterol profiles, and oral and intravenous glucose tolerance tests. All participants will be compensated. For more information, call 2-7119.

Volunteers needed

Please call the Patient Recruitment and Public Liaison Office at 1-800-411-1222 for more information about taking part in any of the following studies:

Schizophrenia. Researchers at the National Institute of Mental Health seek adult sisters, brothers, and parents of family members with schizophrenia for a study of genetic and other differences among them. Compensation provided.

Psoriasis. National Cancer Institute researchers seek people with psoriasis for a new treatment study.

Endometriosis. The National Institute of Child Health and Human Development invites women with pelvic pain associated with endometriosis to take part in a new treatment study.

Allergic Asthma. Doctors at the National Institute of Allergy and Infectious Diseases are seeking people ages 12 – 85, who have asthma symptoms at least three times a week (wheezing, chest tightness, cough, night asthma) for a research study of a new investigational asthma medication. Compensation provided.

Renovations

Masur Auditorium will be closed for renovations during the months of July, August, and part of September.

Pharmacology course

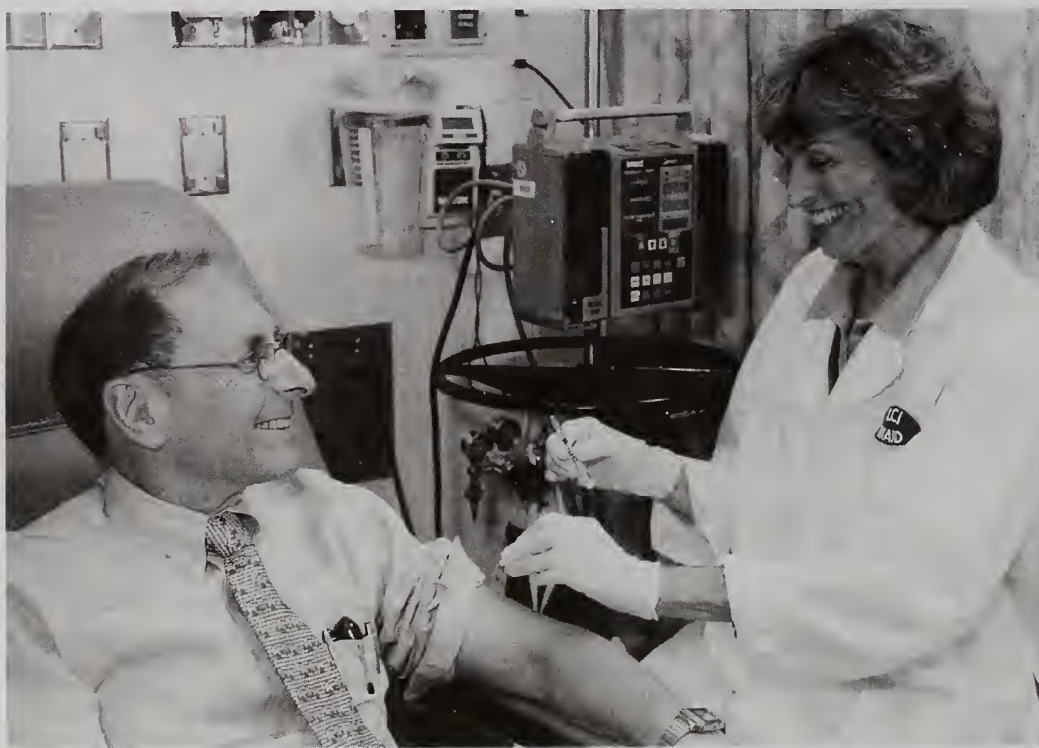
The Principles of Clinical Pharmacology Course, sponsored by the Clinical Center, will begin Sept. 2. The course will be held Thursdays from 6:30 p.m. to 8 p.m. in Lipsett Amphitheater, and runs through April 27, 2000. Topics include pharmacokinetics, drug metabolism and transport, assessment of drug effects, drug therapy in special populations, and drug discovery and development.

An outstanding faculty has been assembled to present the lectures, including Dr. Carl Peck of Georgetown University's Center for Drug Development Science, Dr. Jerry Collins of the Food and Drug Administration, and the Clinical Center's Dr. Arthur J. Atkinson, Jr. Dr. Atkinson is also the course director. Before coming to NIH, he was at Northwestern University, where he directed the Clinical Pharmacology Center, and at the Upjohn Company, where he was in charge of clinical drug development programs.

This is the second year that the course is being offered. Last year, 180 students enrolled, and there was considerable sustained enthusiasm for the course.

Registration is free and open to all interested persons. Syllabus materials will be provided for each lecture. Certificates will be awarded at the end of the course to students who attend 75 percent of the lectures. For more information, including the registration form, consult the course web site (<http://www.cc.nih.gov/cc/principles/>).

Shingles vaccine trial enters phase III at CC



Dr. Philip Brunell receives the first vaccination at the NIH site for the shingles prevention study, from nurse Patricia Hohman.

The 11th floor day hospital was host to history on Thursday, June 17, when Dr. Philip Brunell of NIAID rolled up his sleeve to become the first to be immunized with an experimental vaccine to prevent shingles.

"I've been working on this problem for about 40 years," said Dr. Brunell, an internationally renowned pediatrician and expert on the varicella-zoster virus, the virus that causes chickenpox. "I have a very personal interest in this because zoster is much more common in older Americans and I include myself amongst them. With the hope that this vaccine will prevent or modify shingles, I am going to be the first to roll up my sleeve here at the NIH and get this vaccine."

Herpes zoster, commonly known as shingles, strikes about 500,000 Americans every year. Caused by the same virus that causes chickenpox, it is characterized by a rash or blisters and extreme pain.

The clinical trial has progressed successfully and, with the

immunization of Dr. Brunell, has entered phase III. This advanced stage of trial will further test the vaccine's safety and verify its ability to prevent the disease.

"This is an infection that occurs mostly in older Americans and, as our population ages, the likelihood that we will get shingles also increases," said Dr. Stephen Straus, chief of the laboratory of clinical investigation at NIAID.

Overall, people have a 20 percent chance of developing shingles in their lifetime. After a bout of chickenpox, the virus lies dormant in nerve tissue. The virus may reactivate, causing shingles later in life.

"We believe that by boosting the body's immune response with this vaccine, mimicking a naturally occurring case of zoster, shingles and post-herpetic neuralgia may be prevented," said Dr. Norberto Emilio Soto, principal investigator on the study.

The CC is one of 22 sites across the United States participating in this

large-scale study, which allows all eligible Americans to participate. (See box.)

The trial is unique in size. The research team hopes to vaccinate a total of 37,000 healthy people over age 60 at the sites, with the goal of preventing shingles through this vaccination. Locally, the CC hopes to recruit 1,800 volunteers.

"I think this is the largest vaccine study ever mounted in the United States," said Dr. Straus. "I think this

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Shingles presentation

All are invited to a presentation on shingles, July 22, from noon to 1 p.m., in Bldg. 10, Room 11N235 (Sheldon M. Wolff Conference Room). It will feature an expert speaker on shingles, a slide show, an open discussion, information to share with friends and family, and an opportunity to sign up for the Shingles Prevention Study. The study seeks people who:

- are age 60 or older
- have had chickenpox
- are in good general health--for example, do not have cancer, immune deficiency, or depressed immunity, and
- have *never* had shingles.

Shingles is most common in people over 50 and affects about 2 in every 10 persons in their lifetime. Anyone who has had chickenpox is at risk for developing shingles. Complications can include affects on hearing and vision, and pain at the site of the rash that can last for months or years after the rash has healed.

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is the largest study for the prevention of infectious disease ever done, and it's one of the largest studies ever done for the older population."

Irvin Cohen, a shingles sufferer, looked on as Dr. Brunell was vaccinated.

"I must say, I wouldn't wish the incident of shingles on my worst enemy because for the better part of two weeks, I was absolutely miserable," he said. "The discomfort is so intense at times that you almost

wish that you don't wake up in the morning, and anything that can be done to mitigate that is certainly going to be appreciated, especially by the older population."

The NIAID experimental shingles vaccine research team is looking for healthy adults, ages 60 and over who have had chickenpox and never had shingles. Study participants will be required to make one outpatient visit to the CC, followed by monthly phone calls via a toll-free number for

up to 5 years.

"We have assembled here at NIH a wonderful team of physicians and nurses who will be carrying out the study, and the success now depends on people over age 60 joining us and participating in this simple study," said Dr. Straus.

For more information about the study, please call the Clinical Center Patient Recruitment and Public Liaison Office at 1-800-411-1222.

—by Bonnie Flock

Three from CC assist Kosovar refugees

Faleminderit.

This Albanian phrase meaning "thank you" was one of the most common phrases heard by three members of the CC Medical Record Department (MRD) as they helped process arriving Kosovar refugees at Fort Dix last month.

At the request of the Federal Emergency Management Agency, Jerry King, director of the MRD, sought three employees to volunteer their time in early June at Ft. Dix, in New Jersey.

King was pleased that within 30 minutes of the announcement, he had a pool of nine volunteers.

"It was nice to have so many willing volunteers. I didn't anticipate having so many," said King. "Those who went did a real nice job."

Mark Davidson, Shannon Hall, and Joe Hendery were the three medical records administrators selected for the task.

The three assisted the Fort Dix staff and other organizations by reviewing refugee medical records to ensure proper documentation for entry into the United States. Their main goal and responsibility was to keep families together. Once the required documentation was secured,

they forwarded the information to gain final clearance for the refugee families to be admitted to the U.S. The CC team also made a few changes to the existing medical records system to make it more user-friendly, and assisted with patient registration.

"Having the refugees leave the camp was bittersweet," said Hall. "The entire family is released to join their host family together to start a new life. But on the other hand, they're leaving the safety and security of the camp where they have guaranteed shelter, food, health care, and the camaraderie of the other refugees."

Over the course of the week, there were many observations and surprises for the CC group, who weren't quite sure what to expect when they packed their bags and headed for New Jersey.

"It was a scene of desperate people in a foreign place," said Davidson. "I found it rewarding and personally satisfying to be able to help."

For Hendery, the children made the biggest impression.

"Kids are the same everywhere, I

think," said Hendery. "They were outside playing and having a good time. They're just so resilient, and that's what really got to me. They did have a sense of weariness, but were still behaving like normal kids, playing on the swing sets and running around."

Hall, who shared a room with the attending social worker for several days, heard many stories of loss from her, and also the refugees.

"There was a particular refugee who comes to mind. She was a little older than me," said Hall, 26. "She spoke English very well and was telling me how her family was separated — some fled to New Zealand and Australia. These stories are just unimaginable to most people here in the States. I believe that many of us take for granted what we have, the safety and security."

While working in the patient registration area, Hall had the opportunity to speak with a child while passing out toys.

"I was sitting with this little girl named Emine, and I was talking to her," she said. "We were trying to

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Medical Record staffers Joe Hendery (far left), Mark Davidson (second from left), and Shannon Hall (second from right) are pictured with other volunteers, from the Red Cross, the Veterans Administration, and the Bureau of Prisons. The CC group headed to Fort Dix, in New Jersey, last month to help review the medical records of incoming Kosovar refugees.

...Starbright World connects kids

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the opportunity to take part in this visionary project, and our goal is to make the experience available to as many of our young patients as possible."

There are currently four operational Starbright World computer units in the CC, with hopes of getting more in the future. They are located in the 9th floor playroom, on the 14th floor, and two on the 13th floor.

"Starbright World provides the children with a distraction to what they are experiencing in clinic," said Dr. Wiener. "It also provides them with entertainment and an opportunity to be able to connect with other children who have, or don't have, the same illness.

"It gives them the opportunity to share concerns, worries, fears, hopes, and dreams with others who are also hospital-based," she said. "And it gives them a chance to have fun, reach out, and be creative in a very safe atmosphere."

It is an escape.

"I played the games. The games are fun, really fun," said Heide Rodriguez, 19, who enjoys Starbright World during her visits to the CC. "It really gets your mind off things."

The graphically stimulating games are but one of the many features of this program. It also allows children to enjoy videoconferencing, specialized chat rooms, private e-mail, medical bulletin boards, and interactive multimedia programs that help explain common medical procedures.

Mary Jane Booth, 11, is another patient of the Clinical Center who plays in Starbright World. Like many other pediatric patients, her days are often filled with medical tests, appointments, and doctors.

Starbright World has not only

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communicate when her mother came up to me and rubbed my hair, and said, 'Mire,' which means 'good.' That was just so rewarding, and I think little experiences like that made all of our work worthwhile."

The group found it rewarding to work with the other organizations also offering aid, and was pleasantly surprised by the positive interaction of the different groups.

"One of the things that surprised me is that, over a week's time, we never had a negative working experience," said Hall. "There were so many people working together in such a small place, yet we didn't have any confrontations. Everyone was just so pleasant and had such a team attitude. We were all working

together for the same goal, and it was a nice atmosphere to be in."

Hendery agreed that the small quarters and less-than-perfect conditions didn't affect the attitudes of the volunteers.

"I think that any time you are involved in a volunteer effort, there's a feeling of camaraderie among the people working," said Hendery. "The common goal is to help these people, and it's so tangible because you're right there and you see firsthand who you're helping.

"I felt lucky to be a part of it," he added. "I really didn't know what to expect, but I just knew it would be an unforgettable experience."

—by Bonnie Flock

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Learning to help patients keep faith

This summer the Spiritual Ministry Department welcomes eight new participants to its Clinical Pastoral Education (CPE) program. While striving to strengthen their skills and understanding of the chaplain's role in a clinical setting, these CPE interns will be learning through a plethora of educational activities and extensive patient interaction.

The CPE program is designed to help its participants develop and refine the abilities necessary for working with patients and families in crisis. In the first of their 10 weeks here, the diverse group, which consists of both seminary students and Navy chaplains, have already discovered several pleasant surprises and challenging realities that help create the unique environment of the Clinical Center.

"It's remarkable how much the care here looks at the total person," said Margot Critchfield, one of the chaplain interns. "They approach the patient as a whole person when they take into account the aspects of

spiritual ministry, social work, and recreation therapy. It is a tremendous model for other hospitals."

Intern Scott Carlson added, "My personal experience with hospitals and patients has been so different from what I have seen here. There seems to be a smaller patient-to-doctor ratio, which allows for a much more human approach and connection with patients."

Accommodating the variety of patient faiths at the Clinical Center poses a formidable and important challenge to the CPE interns. As Chaplain Karen Morrow, Spiritual Ministry Department, explains, "We are called on to relate to people from various backgrounds that are not the same as our own. This is a place where we have to help people faithfully, with respect for their beliefs and world view."

Not only do the chaplain interns gain experience through their daily visits with patients, they also have the opportunity to participate in instructional programs, interact with

doctors and nurses, and observe surgical procedures as well.

As the CPE interns are further exposed to helping people in times of illness and distress, they have perceived a sense of hope in patients that reverberates throughout the Clinical Center. Chaplain intern Jane Halpern elaborates: "I've spoken with patients here who are on protocols that may be their absolute hope – or that may give somebody who could be my neighbor or my friend the chance at living a good-quality, prolonged life. You can't say that about many other hospitals."

—by K.C. Gardner

Morrow honored

Karen Morrow, chaplain of the Spiritual Ministry Department, was recently selected as one of five 1999 Outstanding Alumni Award winners from the College of Communication Arts and Sciences at Michigan State University (MSU).

The award recognized both her accomplishments at the Clinical Center and her role as a key member of a pioneer research team studying mass communication behaviors of the inner city urban poor while she attended MSU. Her ability to interact with the teenage African American population was vital to the success of the fieldwork.

Morrow's B.A. degree from the Department of Communications and one of her M.A. degrees in educational guidance and counseling were each attained at MSU. The award was formally presented on May 7 on the MSU campus.

—K.C.G.



Front row (from left) are Spiritual Ministry Chief Ray Fitzgerald, chaplain interns Nestor Nazario, Elliott Watters, Lisa Kenkeremath, and Jane Halpern. Back row (from left) are interns Margot Critchfield, Melinda Russell, Scott Carlson, Donald Fix, and Chaplain Karen Morrow.

MRI center opens

A ceremonial ribbon-cutting marked the opening of the new NIH-Suburban MRI Center last month. Thanks to NIH grants, the Center has state-of-the-art magnetic resonance imaging (MRI) for use in diagnosing heart attack, coronary artery disease, and stroke. CC radiology staff will assist in interpreting some of the MRI scans. (See story in the April 1999 issue of *CCNews*.) Pictured (left to right) are Roger Titus, chairman of Suburban Hospital Healthcare System; CC Director Dr. John Gallin; NHLBI Director Dr. Claude Lenfant; NINDS Director Dr. Gerald D. Fischbach; and Brian G. Grissler, president and CEO of Suburban Hospital.

(Photo courtesy of Suburban Hospital.)



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created a new world for Mary Jane to click into while at the CC, but has allowed her to be a friend to patients in other hospitals and share her compassion and experience with them.

Through videoconferencing, Mary Jane is able to communicate with a boy who is in a Pennsylvania hospital. He was preparing to go through a bone marrow transplant procedure and was scared. Though distance was between them, Mary Jane was able to offer comfort.

"I told him, 'There's nothing to be afraid of. Everything will be alright,'" she said.

Dr. Wiener and the staff involved with Starbright World hope to help as many children as possible enter Starbright World. She is also studying the effects of the program on hospitalized children here and seeks to enroll 30 children in the study. Contact Dr. Wiener or Nataliya Lomakina at 6-3062 for further information about the study or Starbright World.

— by Bonnie Flock

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater

Clinical Pathologic Conference:
Abdominal Mass in a Patient
with HIV Disease, Henry Masur,
M.D., CC, moderator

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater

A Role for Ethics Consultation
in Human-Subjects Research,
Marion Danis, M.D., CC

Treatment of Myelodysplastic
Syndrome with Antithymocyte
Globulin, John Barrett, M.D.,
NHLBI

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater

Perspectives on the Study of
Human Myocardium: Viability,
Vasken Dilsizian, M.D.,
CC/NHLBI

"First Do No Harm":
Management of Healthcare
Providers Infected with HIV,
HBV, and HCV,
David K. Henderson, M.D., CC

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater

Compartmental Analysis in
Pharmacokinetics and Studies
of Pathophysiology, Arthur J.
Atkinson, Jr., M.D., CC

AIDS: Considerations for the
21st Century, Anthony Fauci,
M.D., NIAID

Note: No Clinical Center RoundTables or Wednesday Afternoon Lectures are scheduled for July.